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WRITTEN IN YOUR GENES
A new study underscores the need for representation in genetics research. Scientists looked at whether 25 rare gene mutations known to raise risk for inflammatory bowel disease (IBD) in White European people are also present in Black people. They found that these variants are extremely rare in Black people and that those who do carry them also show genetic signs of some degree of European ancestry. The study demonstrates that these rare gene variants were introduced into the Black population by White Europeans, and it emphasizes the urgent need to research rare disease-specific gene variants in people of all backgrounds, not just a White European background.

SOURCE: Genome Medicine

1.9 million
Number of U.S. adults who have ulcerative colitis.
SOURCE: Preventive Medicine Reports

A NOT-SO-SWEET DISCOVERY
Researchers might have discovered why sugar keeps some people flared up. A normal large intestine, or colon, sheds its lining and generates a new one every 5 days. Any damaged or inflamed cells are lost and replaced with healthy new ones. Scientists looked at this intestinal lining in mice with IBD. When they fed the mice an extremely high-sugar diet, they found that the colon's process of regenerating itself every few days was shut down. Sugar also stunted cell growth in human colon tissue in a lab. The discovery could explain why sweets trigger flares.

SOURCE: Cellular and Molecular Gastroenterology and Hepatology

15 to 30
Most common ages at which IBD is diagnosed.
SOURCE: National Library of Medicine

HEALING IS THE GOAL
When your inflammatory bowel disease is active, you're at risk for serious infections that require a hospital stay. Doctors tended to believe this risk came mainly with highly active disease. But new research suggests that you're not fully out of the woods until your intestine is completely healed. In a study of 55,626 people with IBD, researchers found that even when you have areas of microscopic inflammation—that is, low disease activity—you are still nearly twice as likely to need to go to the hospital for an infection as you are when your intestine is healed. Effective IBD treatment can help avoid this risk.

SOURCE: Clinical Gastroenterology and Hepatology
• Do not receive ENTYVIO® if you have had an allergic reaction to ENTYVIO or any of its ingredients.
• ENTYVIO may cause serious side effects, including:
  ○ Infusion-related and serious allergic reactions can happen while you are receiving ENTYVIO or several hours after treatment. You may need treatment if you have an allergic reaction. Tell your healthcare provider or get immediate medical help if you get any of these symptoms during or after an infusion of ENTYVIO: rash, itching, swelling of your lips, tongue, throat or face, shortness of breath or trouble breathing, wheezing, dizziness, feeling hot, or palpitations (feel like your heart is racing).
  ○ Infections. ENTYVIO may increase your risk of getting a serious infection. Before receiving and during treatment with ENTYVIO, tell your healthcare provider if you think you have an infection or symptoms of an infection, such as fever, chills, muscle aches, cough, shortness of breath, runny nose, sore throat, red or painful skin or sores on your body, tiredness, or pain during urination.
  ○ Liver problems can happen in people who receive ENTYVIO. Tell your healthcare provider right away if you have any of the following symptoms: tiredness, loss of appetite, pain on the right side of your abdomen, dark urine, or yellowing of the skin and eyes (jaundice).
  ○ The most common side effects of ENTYVIO include: common cold, headache, joint pain, nausea, fever, infections of the nose and throat, tiredness, cough, bronchitis, flu, back pain, rash, itching, sinus infection, throat pain, pain in extremities, and with injections under the skin: pain, swelling, itching, hives, bruising, rash, or redness at the injection site. These are not all the possible side effects of ENTYVIO. Call your healthcare provider for medical advice about side effects.
• Before receiving ENTYVIO, tell your healthcare provider about all of your medical conditions, including if you have or think you may have an infection or have infections that keep coming back; have liver problems; have tuberculosis (TB) or have been in close contact with someone with TB; have recently received or are scheduled to receive a vaccine; or if you are pregnant, breastfeeding, plan to become pregnant, or plan to breastfeed.
• Tell your healthcare provider about all the medicines you take, especially if you take or have recently taken Tysabri (natalizumab), Tyruko (natalizumab-sztn), a Tumor Necrosis Factor (TNF) blocker medicine, a medicine that weakens your immune system (immunosuppressant), or corticosteroid medicine.

Please see the Important Facts for ENTYVIO on the following page and talk with your healthcare provider.

ENTYVIO is available for:
• intravenous (IV) infusion: 300 mg vedolizumab.
• subcutaneous (SC) injection: 108 mg vedolizumab.
You are encouraged to report negative side effects of prescription drugs to the FDA.
Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

What is ENTYVIO?
ENTYVIO is a prescription medicine used in adults for the treatment of:
• moderately to severely active ulcerative colitis (UC).
• moderately to severely active Crohn’s disease (CD).
It is not known if ENTYVIO is safe and effective in children under 18 years of age.
**IMPORTANT FACTS**

**ENTRYVIO**

* (en ti’ ee oh) *(vedolizumab)*

For injection, for intravenous use

**ENTRYVIO**

* (en ti’ ee oh) *(vedolizumab)*

For injection, for subcutaneous use

**ENTRYVIO**

* (en ti’ ee oh) PEN *(vedolizumab)*

Injection, for subcutaneous use

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**What is the most important information I should know about ENTRYVIO?**

**ENTRYVIO** may cause serious side effects, including:

- Infusion-related and serious allergic reactions. These reactions can happen while you are receiving ENTRYVIO or several hours after treatment. You may need treatment if you have an allergic reaction. Tell your healthcare provider or get medical help right away if you get any of these symptoms during or after an infusion of ENTRYVIO:
  - Rash, itching, swelling of your lips, tongue, throat or face,
  - Shortness of breath or trouble breathing, wheezing,
  - Dizziness, feeling hot, or palpitations (feel like your heart is racing).

- Infections. ENTRYVIO may increase your risk of getting a serious infection. Before receiving ENTRYVIO and during treatment with ENTRYVIO, tell your healthcare provider if you think you have an infection or have symptoms of an infection such as fever, chills, muscle aches, cough, shortness of breath, runny nose, sore throat, red or painful skin or sores on your body, tiredness, or pain during urination.

- Progressive Multifocal Leuкоencephalopathy (PML). People with weakened immune systems can get progressive multifocal leuкоencephalopathy (PML) (a rare, serious brain infection caused by a virus). Although unlikely while receiving ENTRYVIO, a risk of PML cannot be ruled out. PML can result in death or severe disability. There is no known treatment, prevention, or cure for PML. Tell your healthcare provider right away if you have any of the following symptoms: confusion or problems thinking, loss of balance, change in the way you walk or talk, decreased strength or weakness on one side of the body, blurred vision, or loss of vision.

- Liver Problems. Liver problems can happen in people who receive ENTRYVIO. Tell your healthcare provider right away if you have any of the following symptoms: tiredness, loss of appetite, pain on the right side of your stomach (abdomen), dark urine, or yellowing of the skin and eyes (jaundice). See “What are the possible side effects of ENTRYVIO?” for more information about side effects.

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**What is ENTRYVIO?**

ENTRYVIO is a prescription medicine used in adults for the treatment of:

- Moderately to severely active ulcerative colitis (UC).
- Moderately to severely active Crohn’s disease (CD).

It is not known if ENTRYVIO is safe and effective in children under 18 years of age.

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**Who should not receive ENTRYVIO?**

Do not receive ENTRYVIO if you have had an allergic reaction to ENTRYVIO or any of the ingredients in ENTRYVIO. See the end of the Medication Guide for a complete list of ingredients in ENTRYVIO.

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**Before receiving ENTRYVIO, tell your healthcare provider about all of your medical conditions, including if you:**

- Have an infection, think you may have an infection or have infections that keep coming back (see “What is the most important information I should know about ENTRYVIO?”).
- Have liver problems.
- Have tuberculosis (TB) or have been in close contact with someone with TB.
- Have recently received or are scheduled to receive a vaccine. Talk to your healthcare provider about bringing your vaccines up-to-date before starting treatment with ENTRYVIO.
- Are pregnant or plan to become pregnant. It is not known if ENTRYVIO will harm your unborn baby. Tell your healthcare provider right after you become pregnant while receiving ENTRYVIO.
- Are breastfeeding or plan to breastfeed. ENTRYVIO can pass into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take ENTRYVIO.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins and herbal supplements.

Especially tell your healthcare provider if you take or have recently taken ifosfamide (naltrexone), Tylenol (naltrexone-sulfate), a Tumor Necrosis Factor (TNF) blocker medicine, a medicine that weakens your immune system (immunosuppressant), or corticosteroid medicine.

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**How should I use ENTRYVIO?**

When given in a vein (intravenously):

- You may receive ENTRYVIO through a needle placed in a vein (intravenously) in your upper leg (thigh). ENTRYVIO is given to you over a period of about 30 minutes.
- Your healthcare provider will monitor you during and after the ENTRYVIO infusion for side effects to see if you have a reaction to the treatment.

When given under the skin (subcutaneously):

- You may receive ENTRYVIO as an injection under your skin (subcutaneously) every 2 weeks. You may receive your first subcutaneous injection after at least 2 intravenous infusions in place of the next scheduled intravenous infusion.
- See the detailed instructions for Use that comes with ENTRYVIO about the right way to prepare and give ENTRYVIO.
- ENTRYVIO is provided as single-dose prefilled syringe or single-dose prefilled pen (ENTRYVIO PEN) for subcutaneous use. Your healthcare provider will prescribe the type that is best for you.
- If your healthcare provider decides that you or your caregiver can give your injections of ENTRYVIO at home, you or your caregiver should be shown the right way to prepare and inject ENTRYVIO.
- Do not inject ENTRYVIO until you or your caregiver have been shown the right way by your healthcare provider.
- Always check the label of your prefilled syringe or prefilled pen to make sure you have the correct medicine before each injection.
- Do not shake ENTRYVIO.
- ENTRYVIO is injected under your skin (subcutaneously) 1 time every 2 weeks.

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**What are the possible side effects of ENTRYVIO?**

ENTRYVIO may cause serious side effects, see “What is the most important information I should know about ENTRYVIO?”

The most common side effects of ENTRYVIO include:

- Common cold, headache, joint pain, nausea, fever, infections of the nose and throat, tiredness, cough, bronchitis, flu, back pain, rash, itching, sinus infection, throat pain, pain in extremities, and with infections under the skin, pain, swelling, itching, hives, bruising, rash, or redness at the injection site.

These are not all of the possible side effects of ENTRYVIO. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

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**General information about ENTRYVIO**

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use ENTRYVIO for a condition for which it was not prescribed. Do not give ENTRYVIO to other people, even if they have the same symptoms that you have. You may ask your pharmacist or healthcare provider for information about ENTRYVIO that is written for health professionals.

Manufactured by: Takeda Pharmaceuticals U.S.A., Inc. Lexington, MA 02421

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For more information, go to www.ENTRYVIO.com or call 1-877-TAKEDA7 (1-877-825-3327).

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When you have moderate to severe inflammatory bowel disease (IBD), whether it’s Crohn’s disease or ulcerative colitis, you need medicine that works. But not everyone gets help from the first treatment they try.

“At least a third or more of patients have to change medication at some point in the course of their disease,” says Arafa Djalal, MD, a gastroenterologist at Mount Sinai Hospital in New York City.

If your medication doesn’t control your symptoms so you can live your life, it might be time to talk to your doctor about making a change.

**SHOULD YOU TRY SOMETHING NEW? ASK YOUR DOCTOR ...**

- How long should it take for medicine to work?
- Is it normal to still have the symptoms I’m having?
- Could a different medicine work better for me?
HOW TO KNOW YOUR TREATMENT IS WORKING

The goal of treatment for moderate to severe IBD is to reduce your condition to mild disease or put it into remission completely. When that starts to happen, you’ll feel the difference.

“If a treatment is working for you, the symptoms that were related to the inflammation, such as blood in your stool, diarrhea, and abdominal pain, should begin to improve,” says Nayantara Coelho-Prabhu, MBBS, a gastroenterologist at Mayo Clinic in Rochester, MN.

How long it may take to feel these effects depends on what medication you’re taking and the severity of your disease, she adds. “Your doctor should be able to provide you with a rough estimate of when you should expect some improvement.”

WHY YOU MIGHT SWITCH MEDICATIONS

There are a few reasons that you might discuss a medication change with your doctor. For one, maybe you’ve given the medicine enough time to work but it hasn’t helped you. Or maybe it helped for a while and then your symptoms came back.

In some people, IBD medicines may cause serious side effects, such as recurrent infections or an allergic reaction. These concerns might warrant a change, too.

The solution to these problems could be a change in the dose or frequency of the medicine you’re on now or a different medicine. There are several FDA-approved medications for moderate to severe IBD. If the one you are on now isn’t giving you the results you want, other medicines could help you.

WHY “GOOD ENOUGH” ISN’T GOOD ENOUGH

If you’re taking medicine for IBD but still living with symptoms, that could be a sign that your disease is still active and progressing, which can cause serious problems.

“IBD has the potential to develop into long-standing complications that can severely affect a patient’s quality of life,” Coelho-Prabhu says. So it’s important that you get on medication that works for you.

“You shouldn’t be living with pain, discomfort, or active disease that prevents you from living a full life,” Djalal says. “You should be able to do your normal activities, like going to work and playing the sports that you used to play before having the disease.”
THE HISPANIC POPULATION AND IBD

WHAT TO KNOW ABOUT LIVING WITH AND TREATING YOUR CONDITION

By Rachel Reiff Ellis
Reviewed by Neha Pathak, MD, WebMD Lead Medical Editor

The number of IBD cases in the U.S. are increasing across all cultural backgrounds. But it’s often still considered a White person’s disease, even though in a 2021 study, prevalence of IBD among Hispanic Americans was 418 per 100,000 people, while in the White community, it was 557 per 100,000 people.

The Hispanic community also faces unique issues when it comes to the disease.

IDENTIFYING THE DISEASE

“There’s a bigger delay in IBD diagnosis for Hispanics,” says Joanna Lopez, MD, gastroenterologist at Gastro Health in Miami, FL. “Hispanic patients are not the typical patient population that we think of when we think of inflammatory bowel disease, so for a lot of providers, it doesn’t come to mind first in a differential diagnosis.”

This delay in diagnosis happens even more often for Hispanic people born outside of the U.S., Lopez says.

“They may not seek care, they may not have insurance, or they may have barriers because of their language, so communication with the providers may not express exactly what their symptoms are,” Lopez says. “There are many reasons why the delay may happen.”

One of the big barriers that’s not unique to the Hispanic population but certainly impacts it is the reluctance to open up about bowel symptoms.

“There is definitely a lot of hesitation and embarrassment to discuss symptoms that relate to bowel movements including bleeding and incontinence, and sometimes impact sexual health, across all populations and maybe more so in the Hispanic community,” says Siddharth Singh, MD, gastroenterologist at UC San Diego Health in California.

THE EFFECTS OF DELAYED DIAGNOSIS

The longer it takes to get a diagnosis and start treatment, the higher the risk of complications and the more difficult it is to properly manage the disease, Lopez says.

“IBD is a chronic, lifelong inflammatory condition that affects the intestinal system, and it requires lifelong management, with proper management to be done from the very beginning,” she says.

SIGNS OF IBD

Siddharth Singh, MD, says to be vigilant of these symptoms:
+ Diarrhea
+ Abdominal pain
+ Blood in your stool
+ Pooping more than usual
+ Needing to poop urgently
beginning,” Lopez says. “So the longer patients have undiagnosed disease, usually the more complicated and advanced they are once they are diagnosed and the harder it may be to treat.”

Hispanic people with delayed diagnosis are at greater risk of strictures (areas where the bowel narrows due to scarring), fistulas (a passage between organs or nearby tissues that isn’t normally there), abscesses (an infection that may result in a fistula if not treated), and cancer of the bowel.

Many of these can be avoided easily with prompt treatment, which is why it’s important to increase the awareness of the disease in the Hispanic community and those who treat them.

OVERCOMING BARRIERS
Both Singh and Lopez agree that having a strong relationship with your gastroenterologist is key to good disease management.

Lopez says she recommends seeing an IBD specialist, although she notes that it’s not always possible depending on where you live and insurance limitations. Still, if possible, it can help you have a better outcome and tighter control of the disease.

“At least once a year or every couple of years, see an inflammatory bowel disease doctor,” Lopez says. “If that’s somebody who is also fluent in your language and culturally sensitive to your background, even better.”

Singh is hopeful that with more awareness, an increase in diversity of providers, and technology that helps bridge language barriers, people across all cultures will have quicker diagnoses and better outcomes.

“There should be no fear or embarrassment about this disease,” Singh says. “Treatment has evolved tremendously over the last 2 decades, and most people with IBD live a long and fulfilling life.”

RESOURCES TO HELP

These specific sites can be a support on your journey.

+ Crohn’s & Colitis Foundation (CrohnsColitisFoundation.org/es) provides disease information and support in Spanish.

+ Color of Gastrointestinal Illnesses (ColorOfGI.org) offers community, education, and advocacy opportunities for people of color living with digestive disorders.

Inclusion of these organizations does not constitute an endorsement by WebMD and no endorsement is implied.
HOW I FOUGHT BACK

MY JOURNEY WITH ULCERATIVE COLITIS

By Kimberly M. Hooks
Reviewed by Neha Pathak, MD, WebMD Lead Medical Editor

If you saw me now, you may not recognize the woman I was years ago. I’ve gone from someone in constant pain who hid from the world to someone who speaks and writes about life with ulcerative colitis (UC).

LIFE BEFORE
Growing up, I thought I just had a sensitive stomach. Doctors told my mom I should take laxatives and fiber. These didn’t work at all. Instead, my symptoms persisted as I got older. I started working at a Fortune 500 home company and my GI issues impacted me greatly. I would run to the bathroom all of the time. I worried I was going to be a liability. The impact wasn’t just 9 to 5. It also affected my family life. I would miss some of my daughter’s ballet practices. As a new wife, I had no energy. I felt I wasn’t the same fun person I was when dating my husband.

For our anniversary, my husband and I went on vacation. I spent most of the time in the hotel bathroom. It was horrible! When I came back home, I went to a doctor who finally ordered a colonoscopy. He diagnosed me with a mild stage of UC.

JUST LIKE THAT
When I was diagnosed in 2011, it was all very new to me. I had never heard of UC or Crohn’s disease.

My first visit with a GI specialist didn’t bring much hope. He said, rather bluntly, “You have a chronic disease for which there is no cure. You’ll take these pills for the rest of your life.”

I remember thinking, my God, I’m too young for this!

At the time I was in my late 20s. I didn’t get any information or resources—just the prescription. So I did my research. I read that it’s common in Jewish people, so I was wondering what was wrong with me as an African American woman. I felt alone.

REALLY BAD BEFORE BETTER
After taking oral steroids and rounds of prednisone with no real relief for nearly 10 years, I switched jobs, changed insurance, and found a new GI doctor. He ordered a colonoscopy and upon seeing the results, sent me to the hospital immediately. He said my colon was about to rupture. I was doing everything I knew as a patient.
No one talked to me about diet or lifestyle.

This new GI doctor showed that he was invested in my health. He ordered additional stool tests and blood work. I got iron and blood transfusions because I was very anemic. But because I was diagnosed so late in my journey, my doctor found my colon in a severe state. I ended up having to have emergency surgery to have it removed.

But as I lost part of my body, I found my voice. I found people who looked like me through COGI (Color of Gastrointestinal Illnesses). I learned to advocate for myself. I asked for a nutritionist and now work hard to eat the foods that work best for me. I started writing, posting, and speaking about UC. I now feel more empowered and informed.

**KIMBERLY’S TIPS**

- **Manage stress.** I have diffusers around my house. I journal and meditate.

- **Ask questions.** Go to doctor appointments prepared.

- **Don’t ignore mental health.** Chronic illness is more than physical.
Crohn’s disease and ulcerative colitis (UC) aren’t only hard on your gut. They can also take a toll on your emotions. The care you’ll need for your chronic condition can put a serious strain on your wallet, too. People with Crohn’s or UC often experience financial distress. The stress from the emotional and financial burdens may make your gut symptoms worse. That’s why specialized IBD treatment centers often include psychosocial care, says Laurie A. Keefer, PhD, a health psychologist at Mount Sinai in New York City.

“When you have gut symptoms, fear and anxiety can keep you from leaving your house,” Keefer says. “You can feel isolated. ... When you’re under a lot of stress, you may find your IBD acts up more. It’s that cyclical situation between the brain and gut working together.”

**MIND AND BODY**
How well you’ll do medically and physically depend in part on how you manage your condition emotionally, Keefer says. When you’re down or depressed, you may be less likely to go pick up your medicine from the pharmacy or schedule that colonoscopy. If you have a mental health condition as well as Crohn’s or UC, you’ll want to make sure you’re treating it, too, Keefer says.

Even if you haven’t been diagnosed with a mental health condition, you may still find it tough to accept your gut condition and to face it with hope and optimism, Keefer says. Her advice: Look for supports that can help you with the aspects of your condition you find hard, whether it’s swallowing pills, dealing with your health insurance company, or something else.

“When you build confidence and resilience, you can actually prevent the onset of depression, anxiety, and medical trauma,” Keefer says.
TACKLING FINANCIAL STRAIN

In addition to managing your emotions, you’ll also need to handle any financial concerns you have. Most people with Crohn’s or UC have worries about finances and insurance coverage, says Cassie Ray, director of advocacy for the Crohn’s & Colitis Foundation in New York City.

It helps to understand your insurance coverage plan and make sure your doctor is “in network.” If you or your partner work for a company that has a human resources (HR) department, Ray recommends asking HR if they have an insurance navigator. If you don’t have health insurance, talk to a social worker or someone who can help you get set up with public or private health insurance. In addition to insurance, there are assistance programs to help with treatment or other costs, whether it’s through your hospital or clinic, a charitable organization, or pharmaceutical company.

Ray recommends calling the Crohn’s & Colitis Foundation's IBD Help Center at 888-694-8872 and selecting option 8 from the phone menu for advice and help connecting with resources. Keep in mind that insurance companies often deny claims the first time, especially for prescribed biologics, Ray says. It may take multiple appeals, but she says those medications often get covered eventually.

“Be persistent; be patient,” Ray says. “It can be difficult when you’re stressed with illness and now have to work to find a way to cover treatment, but your health is worth it.”

SEEK SUPPORT

Along with your doctors, these pros may help:

+ Psychologists
+ Pharmacists
+ Dietitians
+ Social workers
+ Assistance programs
+ Information specialists
+ Support groups
Need more information about Crohn's disease or ulcerative colitis?

MyIBD Learning

PATIENT AND CAREGIVER EDUCATION AND SUPPORT

MyIBD Learning education programs connect patients and caregivers with information, resources, and a community of support at every stage of their IBD journey. Our in-person and virtual education programs and On Demand Video Library provide the latest research, treatments, and therapies for Crohn's disease and ulcerative colitis from leading healthcare professionals and patient advocates.

Search for upcoming education programs and helpful resources at: crohnscolitisfoundation.org/myibdlearning